Developing Culturally and Linguistically Competent Health Education Materials

A Guide for the State of New Jersey

Developed by:

Health Systems Research, an Altarum Company

Suganya Sockalingam, Ph.D.

TeamWorks

June 13, 2007

Acknowledgements:

The following individuals served on a workgroup that provided feedback to the consultant responsible for putting this guide together and also served as the New Jersey representatives on the AHRQ Learning Partnership to Decrease Disparities in Pediatric Asthma:

Lisa Jones, MSN, RN, New Jersey Department of Health and Senior Services

Doreleena Sammons-Posey, MS, New Jersey Department of Health and Senior Services

Melissa Vezina, MPH, New Jersey Department of Health and Senior Services

Maris Chavenson, Pediatric Asthma Coalition of New Jersey

Sandra Fusco-Walker, Allergy & Asthma Network Mothers of Asthmatics

Teresa Lampmann, Pediatric Asthma Coalition of New Jersey

Developing Culturally and Linguistically Competent Health Education Materials
A Guide for the State of New Jersey

Introduction

Health promotion is the process of enabling people to increase control over different determinants of health, and to improve their health. Green and Kreuter (1991) further define health promotion as "educational and environmental supports" that create conditions of living that support and maintain health.

Health education is one of several strategies that are used in promoting health. Glanz et al (1990) describe the ultimate aim of health education as achieving "positive changes in behavior."

Managing and minimizing the impact of asthma incidences requires a comprehensive strategy composed of service delivery systems coupled with effective, sustained health education and health promotion interventions. These individual components of a prevention program must not operate in isolation, but must work together toward the well-being of the infant, child, youth, adult and family at risk and the community as a whole. All education activities related to asthma prevention and reduction should contribute to and complement the overall goal of reducing high-risk encounters and behaviors.

Health Promotion & Education

The truth is that both medicine and health promotion have a scientific basis, and both deal with prescriptions for improving the quality of life. The differences are between perspectives: the individual and the societal; the negative and the positive; the curative and the preventive; the reductivist and the holistic. (Downie, R.S., Fyfe, C. & Tannahill, A., 1990)

Successful Asthma Initiatives

Model Practice
Nassau County Childhood Asthma Intervention, Nassau County Department of Health, NY

Promising Practice
Asthma Task Force, Suffolk County Department of Health Services, NY

(See appendix 3)

In order for an education intervention to be effective, it must be culturally and linguistically competent. It is increasingly clear that culture influences all aspects of human behavior including its role in defining illness, health, and wellness and in help-seeking and health maintenance behaviors. Of particular importance is the recognition that health beliefs and practices are passed on from generation to generation.

Cultural Competence

Cultural competence is a set of congruent behaviors, attitudes, and policies that come together in a system, agency or among professionals and enable that system, agency or those professionals to work effectively in cross-cultural situations (Cross, et al, 1989). Cultural competence occurs at all levels including policy-making, administrative, service provision, client involvement, and community engagement.

Five essential elements contribute to a system's, institution's, or agency's ability to become more culturally competent:

1) Valuing diversity;
2) Capacity for cultural self-assessment;
3) Being conscious of the dynamics inherent when cultures interact;
4) Institutionalizing culture knowledge; and
5) Developing adaptations to service delivery that reflect an understanding of cultural diversity (Cross, et al, 1989).

Cultural competence at the service level begins with professionals understanding and respecting cultural differences and understanding that the clients' cultures affect their values, beliefs, perceptions, attitudes, and behaviors. Additionally at the agency level, it involves changes in services and practices.

Cultural competence is a developmental process that evolves over an extended period. Both individuals and organizations are at various levels of awareness, attitudes, knowledge, and skills along the cultural competence continuum.

Some Guiding Principles

- *Family as defined by each culture is the primary system of support and preferred intervention.*
- *Individuals and families make different choices based on cultural beliefs and practices; these choices must be considered if services are to be helpful.*
- *Inherent in cross-cultural interactions are dynamics that must be acknowledged, adjusted to and accepted.*
- *Cultural competence seeks to identify and understand the needs and help-seeking behaviors of individuals and families. Cultural competence seeks to design and implement services that are tailored or matched to the unique needs of individuals, children and families.*
- *Cultural competence involves working in conjunction with natural, informal support and helping networks within culturally diverse communities (e.g., neighborhood, civic and advocacy associations, local/neighborhood merchants and alliance groups, ethnic, social and religious organizations, spiritual leaders and healers).*

Source: Cross et al, 1989

Culture

"the total way of life of a people"
"the social legacy the individual acquires from his group"
"a way of thinking, feeling, and believing"
"an abstraction from behavior"
a theory on the part of the anthropologist about the way in which a group of people in fact behave
a "storehouse of pooled learning"
"a set of standardized orientations to recurrent problems"
"learned behavior"

Source: Clyde Kluckhohn's Mirror for Man, 1949

Culture is learned. This body of learned behaviors acts as a template shaping consciousness and behaviors that are passed on from generation to generation.

Culture is:

Shared by all or almost all members of a group
Passed on from generation to generation
Shapes our behaviors, and
Structures our perceptions (source: unknown).

Culture is ... The way you do the things you do.

Culture — is the sum total of the way of living; including values, beliefs, aesthetic standards, linguistic expression, patterns of thinking, behavioral norms, and styles of communication which a group of people has developed to assure the survival in a particular physical and human environment (Hoopes, 1979).

As defined above many factors need to be taken into consideration when considering cultural influences in our understanding of health, wellness, and disease. Factors specific to different cultural groups include folk remedies, normative cultural values, patient beliefs and practices, and provider beliefs, values and practices.

Often differences in cultural values create conflicts that can affect how services might be accessed or utilized. Cultural competence can serve as a tool in bridging these differences.

Linguistic Competence

> The capacity of an organization and its personnel to communicate effectively, and convey information in a manner that is easily understood by diverse audiences including persons of limited English proficiency, those who are not literate or have low literacy skills, and individuals with disabilities.
>
> Source: Goode, T. and Jones, W. National Center for Cultural Competence, 2006

The organization also needs to ensure that there are policies, structures, practices, procedures and dedicated resources to support this capacity.

Some ways in which organizations ensure linguistic competence is through the availability of:

- Bilingual/bicultural staff
- Cultural brokers
- Telecommunication systems (e.g. multilingual, TTY)
- Interpretation services – foreign language, sign
- Ethnic media in languages other than English
- Print materials in easy to read and low literacy formats
- Varied Approaches to address cognitive disabilities
- Materials in alternative formats
- Translation of documents
- Assistive Technology Devices

Source: Goode, T. and Jones, W. National Center for Cultural Competence, 2006

Linguistic competence also takes into consideration the different aspects of verbal and non-verbal cross-cultural communication with the understanding that communication is driven by different cultural values and beliefs. This has tremendous implications for material development.

23.9% of the foreign-born population of New Jersey lives in linguistic isolation.

(About 19.5% of the population of New Jersey is foreign-born)

A linguistically isolated household is one in which all adults (high school age and older) have some limitation in communicating in English. A household is classified as "linguistically isolated" if no household members age 14 years or over speak only English, and no household members age 14 years or over who speak a language other than English speaks English "very well"....

Data Source: U.S. Census Bureau, Census s 2000, Summary File 3, Tables P19, PCT13 and PCT14.

Health Literacy

Healthy People 2010[1] defines health literacy as "the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions."

The Institute of Medicine (2004) documented that 90 million people have difficulty understanding and acting upon health information. Studies show that persons with low literacy skills are less likely to:

1) Seek and get health services including prevention care,
2) Understand and make decisions based on their own or their children's diagnosis,
3) Understand and respond to informed consent forms,
4) Understand medication instructions for themselves and their children, and
5) Be knowledgeable about the health effects of risks, behaviors, and diseases (AHRQ, 2004)

There are many literacy expectations in health care provision. Clients and their families are expected to:

- Access information
- Access care
- Navigate institutions
- Complete forms
- Provide consent
- Communicate with professionals

- Provide information for assessment, diagnosis & treatment
- Understand directions
- Recognize cues to action
- Follow regimens
- Advocate

Source: Rudd, R.E. (2003) Empowering Disadvantaged Populations.

Additionally it is critical to recognize the implications to the development of health education materials. Different levels of literacy require development of materials at different reading levels and in different formats.

---

1 http://www.healthypeople.gov/

Person-centered planning and education (Family-focused, Family-driven)

There are many definitions for terms such as person-centered planning or education. Likewise, definitions abound for family-focused and family-driven services. The critical element to recognize in any of these concepts is the pivotal individual(s) – the child, youth, adult, and the family.

Person-centered planning is a framework that holds the client/family at the center of the planning process. It is a model that offers multiple approaches to planning so that the process can be tailored to the needs and wishes of the individual/family.

Likewise, person centered education is an educational process in which the client/family is at the center and controls the flow of information. The educator asks questions and listens thereby allowing the client/family to lead the discussion based on their knowledge and needs.

Family-focused and family-driven strategies place the family in the position of authority providing focus to issues and driving the educational agenda. From a culturally competent perspective, educational strategies that are person-centered, family-focused, and family-driven are more likely to appropriately address the diverse cultural values, beliefs, and perspectives of populations being served. The client/family is in control of the information flow and can determine needs and issues.

Although health education materials are developed with a focus population in mind, it is still important to develop educational messages that resonate at the individual level (person-centered). This is possible only when the messages have sufficient specificity that speaks to the individual.

Example of information important in shaping messages:

- Key motivations for behavior change—e.g. pleasing authority figures in the group, becoming more attuned to spiritual needs, etc.

A second-generation Puerto Rican young mother may know about the western treatment model for asthma – yet may defer to her elders and continue traditional treatment vs. prescribed medicine and management. Health education materials that value and address traditional treatments may give her the courage to explore this with her provider and find a way to honor both methods of care.

For health messages to be culturally competent and effective, the following type of information is critical:

- Making statistics meaningful—

For example: Instead of saying 20% of Native American children have 'ever been told they have asthma' in the U.S., personalize the data to:

1 in 5 Native American children have been told they had asthma.

Immediately people are likely to consider their circle of friends and family and imagine the impact. This has the capacity to influence life-altering behavior changes.

Collaboration with Diverse Communities

One of the major aspects of cultural competence is community engagement at all levels of organizational administration and service delivery. A critical guiding value is the involvement of community members in decision-making and leadership functions. Community members with both formal and informal authority can help guide educational efforts. It is most beneficial to engage the community from the onset of an educational development initiative to minimize false starts due to insufficient information.

Identifying and Engaging Community Partners

1. *Identifying Key Community Partners*—Seek representatives who represent and/or serve the focus population including leaders in the faith/spiritual community, elders in the community, natural networks of support, etc.
2. *Inviting Partners to Participate*— Partners must be brought in from the very beginning of the process and not as a rubber stamp at the end. Potential partners should be invited to take leadership in addressing health issues.

Natural Networks of Support

Resources inherent within a community that offer support.

Some examples of natural networks of supports in culturally diverse communities are:

- Extended family relationships
- Friendship networks
- Traditional healers
- Cultural/Ethnic organizations
- Recreational & social clubs
- Ethnic business relationships

3. *Assuring Active and Substantive Participation by All Partners*
   a. Determine need for translation and interpretation services.
   b. Develop a process for a community partner to co-chair the effort.
   c. Begin with mutual education - community including its history, its strengths, its resources, and its concerns vs. medical and scientific aspects of the health issue.
   d. Take time to build trust. Create opportunities to ensure consensus around issues.
4. *Assessing Group Resources*—Determine who has abilities in gathering people in the community, who is a respected voice, who has access to space that can be used for activities related to the effort, who has access to media outlets, who might donate needed supplies, printing, photography, etc., who is good at writing, doing graphics work, etc. Create an understanding that resources come in a variety of ways.

Doing it Right

The purpose of health education/promotion materials is to invoke change in beliefs, attitudes, and knowledge that will lead to behavior changes. These changes come about through a slow, evolutionary process. Changes in human behavior are possible because health messages are made meaningful by the acceptance and inclusion of the individual's cultural frame of health beliefs and practices.

If health education/promotion messages and strategies take a culturally competent approach, the results will show:

a. A true respect for human uniqueness is present, encouraging clients to then question and adapt their own beliefs and practices.
b. Changes in human behavior are possible because of the acceptance and inclusion of the individual's health beliefs and practices in the health messages.
c. Reduction of frustration and possible burnout on the part of educator who now sees clients, families and communities responding to health education and promotion information.
d. Acceptance of the provider, provider group, and organization by the individual and the individual's family and cultural group, thereby allowing the provider to deal with difficult and challenging health education activities.

No single approach to health promotion for diverse racial or ethnic groups will be effective. Approaches must take into account factors such as the particular history, current experiences, level of acculturation, gender, and ages of the target population within a community for whom materials are chosen, adapted, or created. In addition, health promotion depends on utilizing a group's preferred ways of getting information and on the credibility of the information sources. In order to tailor health promotion materials to be effective and culturally competent, efforts must be local—identifying a 'focus' audience within the context of its community. Materials need not be newly developed for each community, but they must be assessed, and if necessary, adapted to meet local needs.

People don't ask for facts in making up their minds. They would rather have one good, soul-satisfying emotion than a dozen facts – Robert Keith Leavitt

Guiding Philosophy in Developing Health Education Materials

Often, health education information is predetermined without any real evidence that the content or the method is relevant or meaningful to the focus group. The undesired effects of such poorly designed educational strategies and health education materials are non-acceptance of health promotion messages, limited success reaching identified outcomes, and/or clients feeling inadequate, offended, or humiliated by the educational encounter.

Incorporating many of the guiding values and prinicples outlined earlier in this guide will ensure that culturally and linguistically diverse clients are more accepting of the health education messages, are more likely to practice new behaviors that might translate to healthier outcomes, and that clients will feel valued and respected in the educational encounter.

Principles to Create Culturally Competent Health Promotion Materials

When choosing, adapting or creating health promotion materials the following principles are critical to ensure infusion of cultural and linguistic competence:

- Acknowledgement of the unique issues of biculturalism and bilingual status of both the health care providers and the service populations.
- Incorporation of cultural knowledge and preferred choices in materials development. Health messages must demonstrate a true respect for human uniqueness and cultural difference, encouraging the recipients to then question and adapt their own beliefs and practices.
- Active community participation at all levels of the development of health messages and materials. This requires members from the target population to be actively involved from the inception of efforts.
- Family as the primary system of support and intervention – this will require consideration of the family as the preferred point and focus of intervention when messages are being developed.
- Importance of cultural assessment – health education and promotion must be based on cultural aspects of epidemiology (concepts of causation and cure).
- Education and promotion should exist in concert with natural and informal health care and support systems within the community.

Developing Culturally and Linguistically Competent Health Education Materials: A Guide for the State of New Jersey

The following checklist has been developed to assist the health educator in several ways:

1. Create health education materials that are culturally and linguistically appropriate;
2. Review existing materials derived from other sources to ensure their appropriateness to the diverse populations being served; and/or
3. Adapt materials that have been developed for other audiences to meet the needs of the population groups being served.

It is unlikely that a single document will meet all the criteria that have been outlined in this guide. The educator will need to determine which criteria may be most critical (given the current circumstances – time, resources, etc.) in creating, reviewing, and/or adapting health education materials.

The more criteria that can be met the more likely that the educational materials meet the standards for cultural and linguistic competence.

The guide can also be used in a multi-step plan for ensuring educational materials are culturally and linguistically competent. Initially the strategy may be to just review and adapt existing materials – thus the content and format sections of the guide may be more relevant. Later when time and/or resources are available to create new materials then the context and process will be equally critical.

Tip for Using the Guide:

When creating, reviewing, and adapting an educational document it might be useful to make a copy of the checklist sheets and use them as a guide to ensure that the materials are culturally and linguistically competent.

I. Context:

The ***context*** addresses issues such as the what, the whys, the who, and the when. It provides the '*meaning or reason'* for the development of the educational material. It guides our thinking regarding the purpose of the educational material. Several factors may guide our decisions of what to develop and how to develop it such as:

- Keeping things fresh – use of different materials at different stages of a child's age
- Provision of relevant information – different information for each succeeding child – more deeper, more complex psychosocial aspects

☐ Current analysis of the environment – clear understanding of the cultural and linguistic differences in the focus population versus the general population

☐ Understanding of the familial constructs, e.g. family structure, dynamics, decision-making roles, etc.

☐ Recognition of the health system infrastructure in relation to health education and promotion and the relationship with focus populations

☐ Review of provider-client relations and the impact of providers as optimal change agents for client health management

☐ Understanding of parental involvement in the health management of the child and/or youth clientele

☐ Materials being created/adapted for first time parents of child with the health condition

☐ Content information relevant for different stages of educational maturation and knowledge development of clients/parents

☐ Identification of a focus audience within the context of the community

II. Process

The ***process*** includes the methods for developing the content, evaluating its applicability, and ways to ensuring it meets the needs of the service population. Materials development is considered as a community-based activity and an on-going formative developmental and evaluation process. The process also takes into consideration the source of materials.

- ☐ A variety of approaches to health promotion for all culturally diverse groups has been considered – dissemination and distribution styles vary
- ☐ Approaches take into account factors such as the particular history, current experiences, level of acculturation and even ages of the target population within a community for whom materials are intended
- ☐ Credibility of the sources of the cultural information are assessed
- ☐ Local efforts for material development have been utilized
- ☐ Materials not newly developed for the community, but has been reviewed, and where necessary, adapted to meet local needs
- ☐ Pre-tested educational materials and methods of delivery with individuals in the focus population
- ☐ Sought feedback via focus groups, interviews, written evaluations or other methods deemed appropriate by the community partners
- ☐ Made any needed changes before going to scale
- ☐ Assessed attitudes and beliefs of the focus audience in relation to the message
- ☐ Changes in specific behaviors considered while developing the materials
- ☐ Changes over time of health outcomes for the population (remember many factors influence this parameter) also considered
- ☐ Continued assessment of changes in population in the community in relation to the health outcome

III. Content:

The third aspect is the content which will consider what messages are critical and how these messages will be conveyed and how well the messages will resonate with the audience for which it is intended.

There are special considerations and characteristics to consider such as:

- In the planning and development of new materials
- In the formative evaluation process of new materials development – reviewing each step
- To assess/review materials from other agencies, states, regions
- To guide what we can do with what we already have – pointers for what we already have
- Developers will know the different strategies that exist and that can be employed
- Different groups learn differently but the basics do not change
- How to do it, fix it, review it

☐ Providing facts regarding asthma - scientifically accurate, credible source, and current

☐ Causations/etiology – information of relevance for families

☐ Individual/Family values, beliefs and practices - culturally appropriate - reflecting beliefs, values and attitudes as well as cultural and spiritual traditions of the intended audience

☐ Practitioner health values, beliefs, and practices - without sponsor or product bias

☐ Concrete examples and practical "how to" information that promotes positive behavior that is focused and manageable

IV. Format

Lastly is the ***format*** that will address language, visuals, style, etc.

Language

- ☐ Language that matches the cross-cultural needs of client and provider
- ☐ Has simple, clear and familiar words
- ☐ Appropriate literacy level (5th-6th grade or lower) and appropriate vocabulary
- ☐ Available in literacy levels and verbal vocabulary of other languages
- ☐ Written in active voice, conversational and personal style: "your baby", "your family"
- ☐ Avoids the use of negative language such as never, should, or must
- ☐ Contains short sentences and short paragraphs

Legibility

- ☐ Uses readable type of at least 12 point font with 1-2 fonts per page to avoid confusion
- ☐ Format resonates with cultural group's preferred ways of getting information
- ☐ Underlining or bolding rather than italics or ALL CAPS to give emphasis
- ☐ Avoids hyphenated words

Visual Imagery

- ☐ Bulleted information
- ☐ Layout/Graphics that are well organized and attractive
- ☐ Information grouped under topic headings
- ☐ Balances white space with words and illustrations
- ☐ Contains appropriate illustrations that are culturally diverse (avoid stereotypes)
- ☐ Graphics depict positive behavior

APPENDIX 1

References

AHRQ (2004) Literacy and Health Outcomes. http://www.ahrq.gov/clinic/tp/littp.htm

Cross, T., Bazron, B., Dennis, K., & Isaacs, M., (1989) Towards A Culturally Competent System of Care Volume I. Washington, DC: Georgetown University Child Development Center, CASSP Technical Assistance Center.

Downie, R. S., Fyfe, C., & Tannahill, A. (1990) Health promotion. Models and values. Oxford, Oxford University Press.

Glanz, K. Lewis, F., & Rimer, B. Eds., (1990) Health behavior and health education: theory, research and practice San Francisco, Jossey Bass.

Goode, T. (2001) Policy Brief 4: Engaging communities to realize the vision of one hundred percent access and zero health disparities: A culturally competent approach. Washington, DC: National Center for Cultural Competence, Georgetown University Center for Child & Human Development.

Goode, T. and Jones, W. (2006) Definition of Linguistic competence, National Center for Cultural Competence.
http://www11.georgetown.edu/research/gucchd/nccc/foundations/frameworks.html

Green, L.W., & Kreuter, M. W. (1991) Health Promotion Planning: An Educational and Environmental Approach. Mountain View, CA, Mayfield Publishing Co.

Hoopes, D.S. (1979). Intercultural communication concepts and the psychology of intercultural experience. In: Pusch, M.D. (Ed.) Multicultural Education, A Cross-Cultural Training Approach. Yarmouth, ME, Intercultural Press.

Institute of Medicine, (2004) Health Literacy: A prescription to End Confusion.

Kluckhorn, C. (1949) Mirror for Man. The Relation of Anthropology to Modern Life. The Quarterly Review of Biology, Vol. 24 (2), pp. 176-177

Mead N., & Bower P. (2000) Patient-Centeredness: A Conceptual Framework and Review of the Empirical Literature. Social Science and Medicine. Vol. 51:1087-1110.

Miller, M.A., & Kinsel, K. (1998) Patient-focused care and its implications for nutrition practice. J Am Diet Assoc Vol. 98 (2), pp. 177-81.

Rudd, R.E. (2003) Empowering Disadvantaged Populations. [electronic slide presentation] Retrieved 7/22/05, from Harvard School of Public Health, Health Literacy Studies Web site

APPENDIX 2

Specific Cultural Issues for Different Populations[1]
Folk Beliefs[2]

Latino Families

1) Ethnomedical therapies for asthma in the mainland Puerto Rican community are commonly used.
   - Home interview with caretakers of 118 Puerto Rican children with asthma who seek care at two community health clinics in an inner city in the eastern United States. Common home-based ethnomedical practices include attempts to maintain physical and emotional balance and harmony, religious practices, and ethnobotanical and other therapies. These therapies include prayer, Vick's VapoRub, *siete jarabes*, aloe vera juice, and eucalyptus tea. The health care practitioner can lower the risk for potentially toxic effects of some treatments by discussing these practices with patients and families. (Pachter. *Arch Pediatr Adolesc Med* 1995;149:982-988)

2) Although there is an overlying shared belief system among mainland Puerto Ricans, Mexican-Americans, and Guatemalans regarding asthma, variation within Latino subgroups is also evident.
   - Community surveys of 160 Latino adults in Hartford, CT; Edinburg, TX; Guadalajara, Mexico; and in rural Guatemala; a 142-item questionnaire covered asthma beliefs and practices. (Pachter et al. Journal of Asthma 2002;39:119-34)
   - Shared belief in humoral ("hot/cold") aspects of health and illness, with the following being considered causes of asthma: cold weather, exposure to drafts and winds, changes in the weather, and not being properly clothed in cold weather.
   - Shared belief in balance in health and illness: "weak lungs," overexertion, and nerves and strong emotions (especially in Puerto Rican sample) as causes of asthma.
   - Mexico and Guatemala reported vitamins, drinking liquids, eucalyptus tea, honey, and praying as treatments for asthma. Guatemala reported herbal teas (chamomile, orange/lemon, bitter, spearmint), garlic, eucalyptus balm, aloe vera or cactus juice, alcohol rub, and applying hot water to the chest as treatments for asthma.

[1] Dr. Jane Brotanek's research on Folk Beliefs

[2] Please note: What follows is not an exhaustive literature review but a list highlighting several important studies that illustrate each major point outlined below.

- Additional studies are needed to explore how these results might compare to other Latino groups and nationalities, like Cuban-Americans, Latinos from the Dominican Republic, and South Americans. This study also did not include data on non-Latino groups (such as African-Americans or Asians/Pacific Islanders, for example), so it is not known to what degree these beliefs are characteristic of Latinos in particular.

- Additional studies are also needed of various racial/ethnic minority groups' views of biomedical therapy, namely anti-inflammatory medications.
  - Study of National Health and Nutrition Examination Survey (NHANES) III (1994-98) revealed 99.8% of children with moderate to severe asthma with parents interviewed in Spanish at high risk of inadequate maintenance asthma therapy (Halterman, *Pediatrics* 2000;105:272-6)
  - In a cross-sectional study in which data was collected via telephone interviews with parents and computerized records for Medicaid-insured children with asthma in five managed care organizations in California, Washington, and Massachusetts, Latino children were less likely than white or African-American children to be using inhaled anti-inflammatory medications (Lieu, *Pediatrics* 2002;109:857-65)
  - The Childhood Asthma Severity Study provided 12-month, retrospective, parent-reported questionnaire data on a monthly basis for children $\leq$ 12 years in a community sample of 1002 children and their families from Connecticut and Massachusetts. Latino children receive fewer inhaled steroids than white children after adjusting for relevant confounders (Ortega, *Pediatrics* 2002;109:E1)

3) Reliance on home remedies for asthma prevention may lead to a higher rate of noncompliance with prescribed regimens.

- In a qualitative study in which 25 mothers of children with asthma were interviewed in their homes, mothers in a Dominican-American community in New York City said that they did not use prescribed medicines for the prevention of asthma; instead, they substituted folk remedies called "zumos." These folk remedies were derived from their folk beliefs about health and illness. (Bearison et al. Pediatric Psychology 2002; 27:385-92).

Native-American Families[3]

1) In Navajo asthma patients, perceptions of asthma and beliefs about the activity of asthma medications influence when and how often asthma medicines are taken, as well as the use of health services.

   - In a study in which ethnographic interviews were conducted with 22 Navajo families with asthmatic children, only 34% of these asthmatics reported current use of anti-inflammatory medications. Many families were concerned about becoming dependent on the medicines and attempted to "wean" the asthmatic from these controller medications, instead of taking them daily as prescribed. These families are hesitant to use long-term controller medications, particularly in the absence of symptoms, because they consider asthma to be a series of acute episodes rather than a chronic disease. (Van Sickle. *Pediatrics* 2001; 108:1-12).

   - Traditional causes of asthma might include lightening and loss of a traditional lifestyle. (Van Sickle. *Pediatrics* 2001; 108:1-12).

   - Use of traditional healing among American Indians is further discussed in Van Sickle et al. *American Indian & Alaska Native Mental Health Research* 2003;11:1-18.A convenience sample of 24 Navajo families with asthmatic members (n=35) was interviewed.

   - Beliefs about triggers can be especially important for Native-Americans, who have a special ritual called smudging, a cleansing ritual in which sage, sweat grass, or tobacco are burned, creating potential asthma triggers. Further studies are needed to examine these issues. This was a finding reported during our evaluation of the cultural competency of asthma educational materials used in Wisconsin.

[3] Please note: The studies described below examined asthma in Navajo families, the group most closely studied. More studies looking at asthma among other Indian subgroups are needed.

African-American Communities[4]

1. In an attempt to reduce the gap in asthma prevalence, morbidity, and mortality among African Americans as compared with Caucasians, the study was designed to identify alternative beliefs and behaviors. To identify causal models of asthma and the context of conventional prescription versus complementary and alternative medicine (CAM) use in low-income African-American (AA) adults with severe asthma, in-depth qualitative interviews were conducted.
    - Sixty-four percent of participants held biologically correct causal models of asthma although 100% reported the use of at least 1 CAM for asthma.
    - *Biologically based therapies, humoral balance, and prayer* were the most popular CAM.
    - While most subjects trusted prescription asthma medicine, there was a preference for integration of CAM with conventional asthma treatment. Complementary and alternative medicine was considered natural, effective, and potentially curative.
    - Three possibly dangerous CAM were identified. *(George, M. et al. J Gen Intern Med, 2006 21[12]: 1317-1324)*
2. The purpose of this study was to investigate the asthma-related beliefs and locus of control held by parents of pediatric patients with asthma and to evaluate how the parents' beliefs compare with those held by health care providers.
    - Parents were less likely than providers to believe that asthma was a chronic illness, but more likely than providers to believe that asthma interfered with their children's lives.
    - Parents believed more strongly than healthcare providers that providers, fate, and God played stronger roles in their child's life.
    - Paradoxically, parents emphasized certain aspects of providers ' control and abilities more than providers themselves did.

    These findings help explain why parents may not adhere to treatment recommendations and provide target areas for intervention. (*George, M. et al. Pediatr Asthma Allergy Immunol 2007; 20[1]:36–47)*
3. This study was designed to investigate community beliefs about caring for childhood asthma and to elicit suggestions for interventions to improve asthmatic children's health. Focus groups were conducted with parents of children with asthma, children with asthma, school staff, and health care and childcare professionals.

[4] Please note: What follows is not an exhaustive literature review but a list highlighting several important studies.

- Data were analyzed for themes, such as disruption of normal living and having to work in a chaotic system, enabling researchers to posit a core belief for each group.
- These core beliefs, together with encompassed other, related beliefs held by group members, guide attitudes and actions about asthma.
- Interventions recommended by focus group participants included creating an asthma play, asthma education, and developing a clinic-based registry to standardize asthma documentation.
- The community's voice is important in assessment and design of health improvement projects. Incorporating the community's suggestions gives the community a sense of contributing to the health care of their children with asthma. *(Peterson, J. et al. Journal of Health Care for the Poor and Underserved 2005; 16[4] :747-759)*

4. Explanatory models (EMs) for asthma among inner-city school-age children and their families were examined as a means of better understanding health behaviors. Children and parents were interviewed about their concepts of asthma etiology, asthma medications, and alternative therapies. Drawings were elicited from children to understand their beliefs about asthma. Children and mothers from a variety of cultural backgrounds including African American were interviewed.
   - Among children, contagion was the primary EM for asthma etiology (53%). Twenty-five percent of children reported fear of dying from asthma, while fear of their child dying from asthma was reported by 76% of mothers.
   - Mothers reported a variety of EMs, some culturally specific, but the majority reported biomedical concepts of etiology, pathophysiology, and triggers.
   - Although 76% of mothers knew the names of more than one of their children's medications, 47% thought their child's medications all had similar functions.
   - Thirty-five percent of families used *herbal treatments* and 35% *incorporated religion* into asthma treatment.
   - Seventy-one percent of families had discontinued medications and 23% reported currently not giving anti-inflammatory medication. Reasons for discontinuing daily medications included fears of unknown side effects (53%), addiction (18%), tachyphylaxis (18%), and feeling that their child was being given too much medicine (23%).

The traditional focus of asthma education is not sufficient to ensure adherence. Asthma education for children should address their views of etiology and fears about dying from asthma. Conversations with parents about their EMs and beliefs about medications and alternative therapies could assist in understanding and responding to parental concerns and choices about medications and help achieve better adherence. (Handelman, L et al. J Asthma. 2004;41[2]:167-77)

APPENDIX 3
MODEL/PROMISING PRACTICES

Nassau County Childhood Asthma Intervention (NCCAI)
Nassau County Department of Health, NY

Target Population: Asthmatic children and their caregivers who reside in low socioeconomic status communities of Nassau County, a large metropolitan suburb adjacent to New York City.

Goals and objectives: The goal of the program is to provide the child's caretakers with the knowledge, skills, motivation and supplies to perform wide-ranging environmental remediation conducive to reducing symptoms of asthma.

Agency and Community Roles: The Health Department (HD) is responsible for most of the initiative's activities. Upon receiving a referral from a community site, health educators and sanitarians perform baseline home evaluations and develop individualized intervention and education plans. Staff provide the equipment and training necessary for wide ranging remediation activities and also conducts six separate hour-long educational modules, provided at two to four week intervals. The modules reference a number of asthma-related topics, including: dust mites, environmental tobacco smoke, cockroaches, pets, rodents, and mold. Children whose caregivers use tobacco are referred to cessation programs, and are eligible to receive free nicotine replacement therapy. Staff also provide families with comprehensive case management services, including referrals for health and social service needs.

Representatives from stakeholder and partner organizations have a key role in the planning and implementation stages by participating in the project management group. This group was responsible for overseeing the adaptation of study protocols, selecting educational materials, and recommending specific outreach activities. Referral sites contribute by identifying families that could potentially benefit from this program. The local asthma coalition is the primary mechanism through which collaboration takes place. Senior HD staff are active members and serve as chairs of several subcommittees, including patient and community education. The program director provides asthma education to health care, community and faith-based member organizations. Several of these organizations have helped identify children now enrolled in the program.

Outcomes: Locally, NCCAI has been a tangible success receiving a second year of funding from the local asthma coalition. Stakeholders and referral sites have demonstrated a high degree of commitment to the initiative since it utilizes an evidenced-based methodology and provides needed case management services. The trust gained by provision of case management services has been instrumental in obtaining access to homes and high levels of adherence to individualized plans. In cooperation with the asthma coalition, the HD is researching additional sources of funding to expand the program.

Excerpted from: http://archive.naccho.org/ModelPractices/default.asp

Asthma Task Force
Suffolk County Department of Health Services, NY

Overview: Suffolk County Department of Health Services (SCDHS) operates a network of 10 community health center sites that provide comprehensive primary care services for patients of all ages. An Asthma Task Force was convened to develop systems approaches to improve the diagnosis and management of asthma within the health centers. The Asthma Task Force developed medical record documents to facilitate superior asthma care (including an Asthma Test, Asthma Management Plan, and Asthma Action Plan), procured asthma equipment (spirometers, nebulizers, peak flow meters, and pulse oximeters) and provided asthma education to health center staff.

Responsiveness and Innovation: This practice has several features that demonstrate promotion of safety and efficiency:

- Patient waiting time is used to complete "Asthma Test" and aid provider in assessing disease severity.
- Physician progress notes are minimized by incorporating "check boxes"
- Progress note forms are color-coded based on disease severity (green-mild persistent, yellow-moderate persistent, dark pink-severe persistent) so provider can obtain an overview of a patient's asthma control with a quick glance.
- Patients assume active role in their health care.

Implementation: The Asthma Task Force developed an Asthma Test, Asthma Management Plan, and Asthma Action Plan. The Asthma Test is used to assess the patient's severity and is completed by the patient (or parent) in the waiting room. It is low-literacy and is available in Spanish. The Asthma Management Plan is a progress note form that aids the provider in selecting medication and other management methods appropriate for the patient's disease severity. The Asthma Action Plan is used to provide the patient with individualized instructions. In addition to the medical record documents, nebulizers, spirometers, pulse oximeters, and peak flow meters were obtained for the health centers.

Evaluation: This practice demonstrated a marked improvement in outcome measures. The number of visits in which disease severity was assessed increased from 10% to 75%, the number of visits when education was provided increased from 5% to 68%, the number of visits when smoking cessation was advised or smoking exposure/status was assessed increased from 13% to 38%, the number of visits in which the patient was given a plan for an emergency increased from 5% to 60%, and the number of visits in which peak flow parameters were given increased from 13% to 28%. Approximately 30% of the health center patients with asthma were reached with this practice. Current efforts are underway to increase this percentage.

Excerpted from: http://archive.naccho.org/ModelPractices/default.asp